

Prejudice and Fear as Influences in Relation to a Successful Organ Donation – Experiences of Immigrants Living in Sweden

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Abstract

Objectives. The purpose of this study was to determine whether fear and prejudice in relation to organ donation and the transplantation of organs may influence the decision to become an organ donor. **Materials and Methods.** Data were collected through four group interviews using open-ended questions and qualitative content analysis. Forty participants, 16 males and 24 females from seven countries, participated in the focus group interviews. **Results.** The analysis resulted in three main categories, and nine subcategories. Fears and prejudice caused by tradition and customs, approval of organ donation by family members, perception of the body as a gift from parents, the influence of religious leaders, knowledge about the religious understanding of organ donation, influence of social ambience on respondents, knowledge of the donation process in the healthcare system, including knowing about life after eventual organ donation, were some of predictors in the decision to agree to organ donation. **Conclusion.** More education on the factors that influence organ donation, more information in schools, health institutions and through the media, as well as more research with the aim of “dispelling” fears and prejudice about organ donation would significantly improve the current situation and result in a larger number of potential organ donors.

Key Words: Prejudice ■ Fear ■ Influence ■ Immigrants ■ Organ Donation.

Introduction

More than 15 million people aged between 30 and 70 years die of non-infectious diseases, every year. About 85% of these “early” deaths occur in low- and moderate-income countries (1). Changing population demographics and an increasing prevalence of risk factors have contributed to the growing demand for organ replacement therapies. The transplantation of organs (TO) and organ donation (OD) are therefore the only option for the restoration of organ function and the prevention of early death for many patients (2). TO and DO restore not only organ function but also quality of

life. In different countries in Europe and around the world, different factors, including owning or not owning donor cards, influence the decision by individuals to be or not to be donors of their organs. The reduced availability of organs and increased difficulty distributing them to patients on the waiting list, the co-modification of organ transplantation, the exploitation of potential donors and the determination of the perception of death have raised ethical and societal questions (3). Religion and religious beliefs may influence the decision to donate organs. In Buddhism and Hinduism, organ donation is seen as an act of generosity, while in Catholicism the leading belief is

that people should help others who are in need for help (4). Attitudes in Judaism vary because of the dilemma between saving lives and benefiting from the dead (5). Even in Islam, there are different views about the transplantation of organs and organ donation (6, 7). Different cultural beliefs may influence organ donation (8). Knowledge of and attitudes towards donation may also affect organ donation (9). Different ages, gender, motivation and the quantity of received information about organ donation, the educational level of informants, geographical location and changing the country of residence may affect the decision to become a donor (10-14). All the above-mentioned factors and all the referenced studies indicate more or less fear and prejudice as factors that can directly or indirectly influence individuals to decide to donate or not. In all these studies, we can read sporadically that these are also the two factors that can influence organ donation. However, there is no study in the world that treats and examines only the two factors that influence the decision regarding organ donation. No study in Sweden has been carried out to assess immigrants' views of fear and prejudice as factors affecting the decision to donate. The author's hypothesis is that different fears and prejudice about organ donation are crucial factors in the decision regarding the transplantation of organs and organ donation.

The present study aimed to determine whether and, to what extent, fear and prejudice relating to organ donation and the transplantation of organs may influence the decision to become an organ donor.

Methods

Design and Participants

The study was designed as a qualitative study using data from interviews with participants from Bosnia and Herzegovina, Macedonia, Turkey, Lebanon, Slovenia, Croatia and Kosovo. The data were collected through four focus group interviews (15). The inclusion criteria were participants from the respective countries, more than 20 years of age,

who had lived in Sweden for more than 10 years. Forty-nine participants took a class on their religion and organ donation. The interview was organised by the Bosnian and Somalian Association in Gothenburg, from June 2022 to February 2023. The four interviews took place in groups the following year, with about one interview a month. Forty participants participated in the interviews, 24 women and 16 men, aged between 40 and 83 years (mean 61.5 years). The men were aged between 46 and 74 (mean 59.0 years) and the women between 41 and 70 (mean 55.5 years). The interviews and all the communications were held in the Bosnian and Swedish languages. The interview groups contained individuals of different ethnic origins, different genders, and different ages. The demographic and clinical characteristics of the informants are shown in Table 1.

Data Collection

Data were collected through group interviews conducted by the first author (FK), using individualised open-ended questions, following an interview guide inspired by Kvale (1997) (16). They began with small talk. The opening questions were "What do you know about the factors impacting organ donation?", "Would you consider donating your own organ or organs to other people?" and "Do you have fear about the organ donation process?" and "What do you think about prejudice in organ donation?". The initial questions were supplemented with other short questions, such as "Could you please tell me more about that?" and "What do you mean by that?". All contact with the participants was organised in collaboration with a key person in a Bosnia and Herzegovina and Somalia Association in the western part of Sweden. Participants who participated in the interview and met the inclusion criteria were asked to participate in the study. When the key person had recruited enough participants, the author of the study was contacted, and the interview was arranged. Printed information about the aim and background of the study was distributed to the participants and repeated to them orally before

Table 1. Demographics and Clinical Characteristics of the Informants

Characteristics	Number
Sex	
Male	16
Female	24
Total	40
Educational level	
Elementary school	35
High school	3
University	2
Total	40
Age (y)	
40-50	8
51-60	12
61-70	6
71-80	7
≥80	7
Total	40
Countries of birth	
Bosnia and Herzegovina	8
Kosovo	5
Lebanon	5
North Macedonia	7
Turkey	6
Croatia	5
Slovenia	4
Total	40
Religion	
Islam	34
Christian Orthodox	2
Catholics	2
Other	2
Total	40

the interview. The interviews were carried out in groups and held in the facilities of the Bosnian and Somalian Association. The interviews were carried out in Bosnian and Swedish by the author of the study, who is bilingual. Some younger participants chose to speak Swedish. All the interviews were therefore first translated into Swedish by the first author (FK), after which a professional translator checked the translation. The interviewer only

interrupted to ask questions or to follow up on the information given. All the participants gave their signed informed consent before the interviews. The interviews lasted between 58 and 120 minutes, with an average of 89 minutes, and were taped and transcribed verbally.

Statistical Analyses

The qualitative content analysis method, in accordance with Graneheim and Lundman (2004), was chosen for the analysis and interpretation of the collected data. This method is suitable for the analysis of qualitative data because, using this method, the researcher is able to condense a large amount of data into a small number of codes, sub-categories, categories and themes (17). The author conducted a manifest analysis of the text. The transcripts were read carefully in order to identify the informants’ experiences and conceptions. The analysis then proceeded by extracting meaningful units, consisting of one or several words, sentences, or paragraphs, containing aspects related to each other and addressing a specific topic in the material. Meaningful units, related to each other through their content and context, were then abstracted and grouped together into a condensed meaningful unit, with a description close to the original text. The condensed text was further abstracted and labelled with a code. Codes that addressed similar issues were then grouped together, resulting in sub-categories. Subcategories that focused on the same problem were brought together, in order to create more extensive conceptions, which addressed an obvious issue (Graneheim and Lundman 2004) (17). The results are presented with direct quotations from the interviews (Table 2).

Research Rigour

According to the criteria for research rigour there is a difference regarding the criteria for quantitative research and qualitative research. Based on this context the criterias for our study, which is a qualitative research study, are transferability, credibility, confirmability and dependability. These

criteria correspond to both internal and external validity as well as objectivity and reliability. These are notions applied in quantitative methods (18). The nature of the present study and its topic, methodology, aims and supposition did not correspond to the criteria regarding quantitative methods. It is therefore on this note the idea behind the development of a specific criteria for qualitative methods is based on. Reliability implies that the same result should be accomplished regardless of who accomplishes the test. In qualitative research, there is a slight impossibility for two researchers, with a recurring study, to reach the same result because of different understandings. However, there is a possibility for them to reach approaching experiences. According to the research rigour, credibility is a reflection of the researchers ability to present and communicate the knowledge and its validity. Factors such as sampling, analysis of methods, the pre-understanding of the researcher and description of the data collection have an influence on the data and its credibility. The transferability in a qualitative study is based on the extent the results are possible to transfer to other contexts (19). It is important that the results are critically evaluated in a similar field and in regard to previous studies. The analysing of text was performed with attention to unitizing – segmenting the texts for analysis – sampling- selecting an appropriate collection of units to analyse. Reliability – different researchers making codes consistently, and Validity – using a coding scheme that adequately represents the specified phenomena (18, 19).

Ethics Statement

Since there was no physical intervention and no information on individual health issues was involved in the study, there was no need to involve the ethical board, in accordance with Swedish Health and Medical Services Act (2017) (20), and according to Act on ethical review of research involving human subjects (21). The World Medical Association Declaration of Helsinki (1964) (22), was followed carefully. The informants' identities were protected, i.e. their names and personal identity numbers were not stated in the recordings or any publications. The audiotapes used for the interviews were stored in a locked safe at the hospital. The identity of the participants could therefore not be traced. The study information given to the participants included its voluntary nature and the fact that they could withdraw at any time without incurring penalties or losing access to services.

Results

The analysis of the text resulted in three main categories and nine subcategories, based on the participants' description of their thoughts about fear and prejudice as influencing factors regarding OD. The categories, together with the subcategories, are presented in Table 2. The categories were: insufficient information, religious influences, socio-cultural influences and cost related issues.

Table 2. Overview of the Theme, Categories and Subcategories

Categories	Subcategories	Theme
Insufficient information	Knowledge about donation process	–
	Fear about life after donation process	–
Religious influences	Influence of religious leaders	–
	Influence of knowledge in religion	Prejudice and fear as predictors in a successful organ donation
Socio-cultural influences	Influence from family members	–
	The gift from the parents	–
	Influence of the social ambience	–
Cost related issues	Knowledge about fees in donation process	–

Insufficient Information

During the entire interview, it became clear that that all the participants in the study are only physically in Sweden, but that they are mentally and with all their hearts in their home countries. Ignorance and lack of information about how an organ donation process works, how the health system works, the payment obligations during the process, the duties and rights of the person who donates his/her organs, as well as what happens after the organ donation is complete, were just some of the questions about which the participants in the study had no idea. Fears and prejudice weighed most heavily and were most frequently expressed in this section.

Knowledge of Donation Process

Knowledge relating to the process of organ donation was scarce among the majority of participants. Most of them were ashamed to talk about the fact that they do not know how an organ donation takes place. In this case, their knowledge and information were based on the stories of acquaintances and family, on the retelling of various fears, as well as on the basis of various prejudices.

“I heard that, a long time ago, a guy applied to donate a kidney and they removed all the organs he could donate at the hospital.”

“I heard that, if you get hurt, nobody wants to save you because they need your organs.”

“I’m afraid of being in hospital.”

Fear about Life after Transplantation

Thinking about the future, thinking about the existence of descendants, as well as about life after organ donation was present in a few participants. Again, there was ignorance, a lack of knowledge, as well as distrust in the healthcare system.

“After the operation, you have to be on sick leave for a long time and I don’t have the funds for that”

“I heard that the operation has to be repeated several times... more absence from work... more risk of dismissal. No thanks.”

Religious Influences

Almost all the participants regarded themselves as religious and the influence of religion regarding organ donation was strong. People who preached religion, knowledge of the connection between religion and organ donation, as well as influence from the people around them, were strongly emphasised by all the participants in the study. Prejudice and fear were present here.

Influence of Religious Leaders

From the point of view of blindly listening to everything a religious leader says and blindly believing it, thoughts between the participants were shared. While some participants believed everything their leader said, there were some who took this with a “pinch of salt” and something that needed to be checked carefully. While some did not want to disappoint their leaders, there were others who were afraid of what their leaders would think of them.

“I don’t know how my leader would react, if I said something against him.”

“Once, what my leader said about organ donation wasn’t true, but I didn’t dare say anything.”

Influence of Knowledge in Religion

The same discussion among the participants was about whether religion allows organ donation. On the one hand, there were those who believed that religion allows organ donation, but not its abuse. On the other hand, there were people who strictly believed that religion does not allow organ donation. Fears of the thought of making a mistake, of hurting their religion, as well as the fact that prejudice was an integral part of this life were present in all the participants in the study.

“I’m afraid to think about organ donation because my religion doesn’t allow it.”

“I heard that, if organs are donated, you have no place in the other world, in your religion.”

“All religions allow organ donation, but I’m afraid.”

Socio - Cultural Influences

According to participants in this study, cultural and culturological factors linked to fear and prejudice in relation to decisions to donate their organs were multifaceted. Despite the fact that the majority of them have lived in Sweden for more than 20 years, their traditions and customs from their respective countries were so strong that it felt as though all the participants were “imprisoned by” them. The influence of the family, who had to approve every part of the donation process, was no less important. The participants who came from non-European countries perceived their body as a gift from their parents. In all their narratives, fear and prejudice were interwoven, so that, if there was more fear, then there was less prejudice and vice versa.

Influence of Family Members

Connection to the family and family members on the issue of organ donation was equally strong. No matter how urgently the organ needs to be fixed and how urgently the person needs it, the family must approve this. Participants stated that it sometimes happened that the family approved the donation, but that it was usually too late. Many times, they did not even dare to ask about organ donation.

“Once we needed a kidney for my brother, but we didn’t ask for a donor... we were afraid of the reaction.”

“If you are not liked by the family, then you have no place in the next – real life.”

A Gift from the Parents

All the participants placed their parents next to God. The will of the parents was their own, they showed a great deal of respect to their parents, they did everything to make their parents proud and they thought that their body and all their organs were created by God and given by their parents. Fear and prejudice were also present here.

“I don’t have the right to give my organs to others because I don’t own them.”

“I heard that a person donated his organs and dreamed about his parents for many years.”

Influence of the Social Ambience

All the participants in the study felt uncomfortable when it came time to talking about their friends, acquaintances, neighbours and work colleagues and about donating organs. Their thoughts on organ donation slowed down the way their surroundings functioned, because they did not know how the people around them (their environment) would react if they decided to donate their organs.

“I don’t dare to think about how the people I know would react if they heard about my possible plans for donation.”

Cost Related Issues

An additional burden, additional fears and the awakening of prejudice were also caused by daily events related to warfare, high living costs and increasing living standards,

Knowledge about Fees in Donation Process

In this subcategory, the majority of participants were convinced that they were obliged to pay the price of organ donation. Ignorance of the way the health system functions triggered additional fears among all participants.

“I am afraid that, if I decide to donate organs and if something happens to me, my family will have to bear all the costs.”

“Generally, the situation in the world is difficult and I don’t need additional expenses.”

Discussion

The present study is the first study in Sweden and in the world to investigate only the relationship between fear and prejudice as a direct influence on the decision relating to the transplantation of organs and organ donation. This is also the first study to include informants from seven different countries and two different continents. In qualitative studies that are based on interviews where the goal is to interpret texts at different levels, a qualitative content analysis is a suitable analysis

method (17). The authors considered this appropriate in order to illuminate the purpose and see it from its parts and as a whole.

The goal was to get a result that is based on an analysis that is possible to follow by being transparent but that is still abstract and innovative. The choice to proceed with a theme was then made. By making the analysis process joint, the risk of the material that responded to the purpose getting lost was eliminated. To further eliminate this, the codes were compared against the meaning units to ensure that the meaning was not lost (17). The results of the study are based on the characteristics of the participants – one group of 40 participants, of which 24 were women, and 16 of them were males. The majority of them had completed an elementary-school education, most belonged to the religion of Islam, and were between 50-60 years old. All of them spoke Swedish and the participants from the Balkans spoke Bosnian. The hypothesis the author puts forward in the introduction to the study – that different fears and prejudice about organ donation are crucial factors in the decision to transplant organs and organ donation – proved to be more than accurate in the present study. Regardless of the dialogue segment and the part of the interview, fears and prejudices in organ donation were visible among respondents in the study. Based on all the conducted interviews, the authors of the study have the impression that the participants in this study are somehow “stuck” in their thinking about anything other than their fears and prejudice.

On top of all the other daily obligations and burdens, “shackles” from the insufficient information about organ donation, the influence of religion and knowledge of the attitude of religion regarding organ donation, as well as the socio-cultural influences in decision to organ donation and cost related issues, prevented the participants in this study from thinking at all. On the issue of organ donation and transplantation, it appears that the participants in this study simply do not have that subject in their lives. The result of the present study showed that the majority of the participants had not reached the level of thinking

about organ donation. In the part of the interview that talks about the insufficient information about organ donation and the process after the organ donation that can affect the respondents and their decision to donate organs, answers about patriotism and the fact that the majority of the respondents live in Sweden only because the situation in their home countries is bad dominated.

Despite the fact that all the respondents knew the Swedish language and most of them were educated and worked in Sweden, most of the fears and prejudices they expressed during the interview regarding the socioeconomic factors that influence their decision were precisely caused by ignorance regarding the functioning of the process, the organization during organ donation as well as ignorance of the organization of the health care system of the state where they had been living for the last 20 years or more. Perhaps the answer to that question should be searched for in the very pronounced patriotism that all the respondents visibly displayed. The first fears and prejudices regarding the information and knowledge that hinder organ donation were precisely the ignorance about the donation process as well as the functioning of the healthcare system. This supports the findings of other studies around the world, where knowledge level has been shown to predict people’s attitude towards OD. Those with more knowledge were more likely to participate in OD (23). The authors found that people looked at various magazines about religion and health and thus gained additional knowledge, watching television and using the internet also helped study respondents to gain more knowledge. In another study, it was initially shown that respondents know a lot about OD (11, 24-26). It is good for people to find information about both OD and the healthcare system themselves. Ignorance and lack of interest, as well as fears and prejudices about organ donation were a bad combination for the decision to donate organs among all respondents.

The result of our study also shows that ignorance of the functioning of the healthcare system, and the process of organ donation leads to ignorance about the cost of organ donation in Sweden,

as well as the fact that patients in Sweden do not pay for surgery (11). The respondents of the study did not show any more knowledge about the healthcare system and the condition of possible donors after the operative process. The combination of fears and prejudices of all respondents made the situation only worse. One study from Denmark showed that the use of the healthcare system was caused by the economic situation, the level of education, the level of income, as well as the fact that the more diseases the patients had, the more they sought and used the health system (27). Fear and prejudice after possible organ donation were also present in several participants of the study. Similar results to the results of our study were shown in other studies in patients who underwent kidney transplantation and who expressed similar fears and concerns. Study participants were concerned about the safety of the surgical transplant procedure, as well as fear of possible postoperative complications. For patients who were far from hospitals, fears were most often about insufficient and irregular care, which could lead to additional health complications of the subjects (28). This included a distinct concern about kidney transplantation failure, leading to a return to dialysis and significant time spent away from home trying to find another donor (28-30).

A large number of participants in the presented study belonged to the Islamic religion; their knowledge of Islam's position regarding organ donation was thin and was based on the teachings of one imam. Sometimes that knowledge was good and sometimes it was at a low level. Most of the participants in the presented study were of the opinion that Islam as a religion opposes organ donation. An additional barrier was the influence of the environment on people's thinking and decisions about organ donation. In a similar study (31), it emerged that Islam as a faith allows organ donation, but few Muslims were aware of this. Muslims in the study want clear messages from their religious leader. This would make them less uncertain about their position, as they hesitated to take a position until they received the go-ahead from their leader. Coming to the next life intact with one's

body whole, not mixing different organs with different bodies and preferably donating one's organs to those who belonged to the same religion were also views that emerged in the study (32).

Most of the participants in the study were positive about organ donation, but they did not know their religion's point of view (31, 32). Religion is not the only factor having an impact on people's choice to donate. Socio-cultural influences, tradition and customs, influence from the family and the perception that they do not own their body but that it is a gift from their parents also contributes to their final stand regarding the question of donation. A study along the same lines as the present one, which dealt with Chinese people living in Canada, showed that culture, traditions and customs were very important in the decisions about organ donation. Talking about death was an unwelcome topic, which in turn caused the participants to have difficulty talking about organ donation (33). A similar study found that older Asians living with their old traditions and customs found it difficult to think about and donate their organs after death. The younger generations, on the other hand, who had been affected and influenced by western culture, had changed their opinion and were more positive about organ donation. This did not mean, however, that they were prepared to forget and bury the old traditions and customs (34). Unfortunately, this is not the case in our study with participants from several countries and two different continents, with life in the West for more than 20 years but with retained cultural and cultural customs. Some cultures perceive organ donation as harming the body and that the body and all the organs are gifts from the parents and ancestors (35).

On the other hand, some traditions believe that life is a gift and gifts should be given, which was a positive attitude towards organ donation (34). Fear of how the family and family members would react to the need for a donor or organ donation was another obstacle for most participants when it came to thinking about organ donation. The fears were so great that organ donation was not even thought about, instead the person who needed the organ surrendered to his fate. Similarities could also be

found regarding donating an organ to someone else. The fear in searching for a potential organ donor or deciding to donate personal organs was shown in another study. Potential recipients reported particular difficulties in asking family or others to be evaluated as directed kidney donors. Finding a donor was more challenging when there was a high level of shared medical comorbidity in families and communities that increased the expected risk to the donor. This most often led to the decision not to donate organs nor receive organs from other people (36). In a study, in which 499 teachers from Bosnia and Herzegovina participated, the majority of them clearly presented positive thoughts about organ donation. The teachers came from the three major religions, Orthodox, Catholicism and Islam, and would accept an organ from both living and deceased donors. However, there was a difference between the religious groups regarding this issue ($P=0.063$). Some also stated that they would donate from a deceased member of the family, while others were uncertain about this type of donation. There was no significant difference between the religious groups that were questioned ($P=0.769$). Regarding the question of who they would donate to, the majority answered that they would donate to a relative, while only a few said that they would donate to someone they did not know. A significant difference between the groups could be noted here ($P=0.002$) (10). Unfortunately, the result of that study contradicts the result of the presented study, because the study participants, due to various fears and prejudices, did not reach the stage of thinking about organ donation and it was impossible to think about the process. Thoughts about the future, about the time after the operation and about possible complications, were followed by fear that the family will bear costs. Economic situation globally made matters even worse. A similar study where authors of the study hypothesized that African American (AA) living kidney donors have a greater risk of kidney failure than European American donors. Apolipoprotein L1 (APOL1) gene variants in AA may be associated with this difference. Semistructured interviews assessed

attitudes about APOL1 gene testing, willingness to undergo APOL1 testing, hypothetical donation decisions with two APOL1 variants, and demographics. Participants were concerned about insurance coverage and costs of APOL1 testing and feared that APOL1 genetic test results could discriminate against AA (37).

Every society and social community must work to ensure that every day there are more organ donations, transplants and therefore more lives saved. However, neither medical progress, nor improved economic growth, nor perfect technological equipment, nor changes in legislation can bring an increased number of organ donations without high social responsibility and a high degree of civic solidarity. The secret of success in organ donation and transplantation is continuous, careful, dosed but honest information to the public and also education of the population.

Study Limitations

The present study has some limitations. The interviews were held in mixed groups, with subjects from seven different countries, two continents and of both genders, which may have made the participants nervous, making it difficult for them to concentrate during the interview and the discussion. Another limitation may be that the interview took place during various activities on the premises of the Bosnian and Somalian Association, so at the time it was very noisy, which caused anger, nervousness and difficulty concentrating for some participants.

Conclusion

The results of the present study show that there are many different opinions that influence participants' decision-making on the subject of organ donation. These views are associated with people's cultural and religious affiliation, level of knowledge, sociocultural influences and how well the discussion within the family on the subject of organ donation works. Today's global geopolitical situation also influenced the participants in their thinking

about organ donation. However, the greatest barrier in the process of starting to think about organ donation was various kinds of fear and prejudice. The healthcare system should work more actively to make information and knowledge on the subject of organ donation more accessible to the population. This may mean that more information in different languages about where different religions stand on the subject of organ donation is presented. It may also mean that the information should have a cultural angle in view of today's multicultural society, which exists in both Sweden and the world as a whole.

What Is Already Known on this Topic:

The transplantation of organs and organ donation are the option for the restoration of organ function and the prevention of early death for many patients. Organ donation restores not only organ function but also quality of life. Different cultural beliefs, knowledge of and attitudes towards donation, ages, gender, motivation, and the quantity of received information about organ donation, the educational level of informants, geographical location and changing the country of residence, and even fear and prejudices may affect the decision to become a donor.

What this Study Adds:

Despite the top scientific and medical achievements in the form of organ donation and transplantation, there are still obstacles and factors that hinder their realization. These factors are associated with people's cultural and religious affiliation, level of knowledge, sociocultural influences and how well the discussion within the family on the subject of organ donation works. Today's global geopolitical situation also influenced the participants in their thinking about organ donation. However, the greatest barrier and brake in the process of starting to think about organ donation was various kinds of fear and prejudice.

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